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Advance Directives and the Psychological Challenges of Surrogate Decision-making

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Chapter in the book, *Decision-Making Near the End of Life: Recent Developments and Future Directions* (James L. Werth, Jr. & Dean Blevins, Eds.)

This chapter is a revised and expanded version of an article that appeared in *Death Studies*.

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## What Would Terri Want?

### Advance Directives and the Psychological Challenges of Surrogate Decision-making

The tragic final chapter of Terri Schiavo's life story was unique in many ways (see Cerminara, this volume). Even in an era saturated with celebrity trials and confessional television talk shows, seldom has such an exquisitely personal decision been elevated to the level of full-blown, 21st century style public spectacle. Discussions normally held in reverent tones within the dimly lit corridors of hospitals and hospices were magnified by a 24-hour news cycle and an ongoing culture war into a national conversation--a national shouting match at times--with individuals, interest groups, and even the United States Congress aligning themselves with one or the other side of a horribly fractured family to engage in an agonizingly difficult debate over the relative value of a human life versus the essentially human right to decide how one's life should be lived (and therefore ended). The situation seemed uniquely cursed with every difficulty that might befall a family striving to make the right decisions for an incapacitated loved one. Irreconcilable differences between family members about the appropriate course of action, the lack of any written documentation of Terri's wishes about the use of life-sustaining technology, and ambiguity about her level of disability and prognosis for recovery, all created a confluence of uncertainty that seemed only to fuel the moral outrage among active partisans and make simple, comfortable resolutions difficult for almost any thoughtful observer.

In many other ways, however, the issues faced by Terri Schiavo's family were not at all unusual. Every day thousands of families in the United States and around the world must make decisions about whether to prolong a loved one's life "artificially" with medical treatment.<sup>1</sup>

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<sup>1</sup> It must be noted that decisions about the use of life-sustaining medical technology are really only a relevant concern in the developed world. In the majority of countries around the globe, concerns about stopping medical treatment for individuals who no longer believe their life is worth living are overwhelmed by concerns about providing medical treatment for individuals whose lives are still clearly worth living.

Every day families disagree about how such decisions should be made, are uncertain about what their loved one would have really wanted, and wrestle with doubts about giving up the fight for their loved one's life too early, or too late. The end of Terri Schiavo's life may have been unique in the number of different factors that conspired to complicate decision-making on her behalf, but taken individually the challenges faced by the Schiavo and Schindler families were all too common ones, and thus an analysis of them can help generate insights that are applicable to the difficulties inherent in end-of-life medical decision-making more generally.

In this chapter, I will use the Terri Schiavo case as a springboard to review psychological research on end-of-life medical decision-making generally, and the use of instructional advance directives (i.e., "living wills") in particular. I will identify three points of uncertainty and disagreement that were brought into sharp relief in the Schiavo case, which represent general categories of problems faced in almost all instances when decisions about the use of life-sustaining treatment must be made for incapacitated individuals. I will conclude with a discussion of some lessons we might learn from the Schiavo case about how to better approach such decisions in the future, but with a disclaimer: There is no easy fix that will make end-of-life decision-making simple and conflict-free. The line between life and death will nearly always be blurry, and there likely will never be a sure way of knowing the wishes of an individual left wishless by ravages of injury or disease. Despite many commentators' quick leap to endorse living wills as the sure path to avoiding Terri and her family's sad fate, resolving the uncertainty and conflict inherent in end-of-life medical decisions will not be as easy as just filling out a form.

#### Self-Determination, Surrogate Decision-making, and Substituted Judgment

The fundamental right of individuals to control the important decisions in their lives, especially regarding their own health and bodily integrity, is well founded in United States law

and embodied by traditional American values of personal liberty and privacy. When medical decisions must be made near the end of life, however, this basic right to self-determination becomes complicated in two important ways.

First, although ethicists often argue that there is no morally-relevant distinction between identical outcomes brought about by acts of commission (doing something) versus acts of omission (not doing something), lay people, legislators, and judges often do see an importance difference (Baron & Ritov, 2004; Spranca, Minsk, & Baron, 1991). A good example of this point is that although the right of seriously ill individuals to choose not to avail themselves of life-sustaining medical treatment is relatively noncontroversial as a matter of both law and public opinion, whether these same individuals have the right to take *active* steps to end their own lives remains extremely contentious (Dresser, 2003; Pew Research Center, 2006). This is most obviously true in cases where medication is used to hasten death, as in the classic physician-assisted suicide scenario, or in the physician-condoned-but-unassisted death described in Nicola Raye's touching story of her father's passing (see Raye's chapter in this volume). But the same psychological distinction also underlies the ethical difference many people sense between choosing not to initiate life-sustaining treatment in the first place (an act of omission), and stopping life-sustaining treatment that has already begun (an act of commission). In this chapter, I will focus only on decisions about whether to begin or continue life-sustaining treatment, and will not deal with the important set of psychological issues revolving around the most active forms of hastened death like physician-assisted suicide. In particular, my focus will be on situations like those faced by Terri Schiavo's family, as well as Laura Crow and her father (see Crow's chapter, this volume), in which decisions about the use of life-sustaining medical treatment must be made for individuals who can no longer speak for themselves.

This brings us to the second complication that often faces the exercise of patient self-determination near the end of life. Exercising one's right to choose for oneself is a straightforward affair as long as that self is conscious and competent to make decisions. Unfortunately, in many cases where decisions have to be made about the use of life-sustaining medical treatment, these decisions must be made after the individual is already too sick to speak for himself or herself (e.g., Bradley, Walker, Blecher, & Wettle, 1997). As a legal matter, it is well established that current incompetence does not diminish a formally competent individual's fundamental right to self-determination (*Cruzan v. Director, Missouri Department of Health*, 1990; Dresser, 2003; see also Cerminara, this volume). As such, Terri Schiavo retained her legal rights to make her own medical decisions despite the fact that near the end of her life she had been unable to speak for herself for more than a decade. The problem of course is a logistical one. How can people like Terri Schiavo or Laura Crow's brain-injured brother exercise their fundamental right to make their own medical decisions?

The key is that someone else must make the decision for them, but do so in a way that faithfully represents the decisions they would have made for themselves if they were able. This process is referred to as *substituted judgment* (Baergan, 1995; President's Commission, 1983), and it is generally accepted as the most desirable method of making decisions for incapacitated patients precisely because of the ethical priority accorded to self-determination in medical decision-making (Buchanan & Brock, 1990; President's Commission). That is, rather than representing a surrogate decision maker's beliefs about what is best for the patient, the substituted judgment standard requires surrogates to remove their own wishes from the decision-making process, and strive only to represent the *patient's* preferences regarding the use of life-sustaining medical treatment. In this way, the interpersonal judgment can be *substituted* for the

personal one, and the incapacitated individual can maintain, through a surrogate decision maker, the ability to express choices even though he or she currently lacks decision-making capacity.

From a legal and ethical standpoint then, the decision about whether to terminate the provision of nutrition and hydration to Terri Schiavo was her decision to make. Because Terri was no longer able to make that decision for herself, however, the task facing her loved ones was to ask themselves the essential substituted judgment question, “What would Terri want?”

It is my contention in the following sections that when faced with the prospect of a seriously ill loved one, people have difficulty both asking and answering this important question. Honoring the wishes of an incapacitated individual is no simple psychological feat. Not only must the surrogate remain focused on the task of predicting *the patient's* wishes in the face of other competing standards that might be used to make decisions on the patient's behalf, but prior indications of the patient's wishes (even formal ones recorded in advance directive documents) are seldom as helpful as most people imagine when it comes to predicting how the patient would make a specific decision about the use of a particular medical therapy in a specific set of clinical circumstances. To be sure, it took a unique convergence of medical uncertainty, family dynamics, and historic and cultural forces to catapult Terri Schiavo into the national spotlight. Still, an analysis of the points of conflict in the Schiavo case can be instructive about the problems surrounding end-of-life decision-making more generally in that the very intensity of the conflict that surrounded that case serves to highlight issues that are actually quite common, but normally struggled with in less dramatic fashion.

The three central points of uncertainty, and therefore conflict, in the Schiavo case concerned: (a) the appropriate standard by which to make decisions on Terri's behalf, (b) the specific nature of Terri's wishes about the use of life-sustaining treatment, and (c) the true nature

of Terri's level of disability and prognosis for recovery. These points will be discussed in turn, first in terms of how each played out in the Schiavo case specifically, and second with an emphasis on identifying issues of general concern in end-of-life medical decision-making.

### Conflicting Values for End-of-Life Decision-making

Based on the precedent set by *Cruzan v. Director, Missouri Department of Health* (1990) and supported by Florida State Law, the legal decision regarding the removal of Terri Schiavo from artificial nutrition and hydration hinged on the provision of "clear and convincing" evidence that this act was consistent with Terri's wishes. The legal arguments presented by the two sides were thus primarily framed in terms of honoring Terri's wishes, and therefore, her right to self-determination. In fact, the ability of Terri's husband Michael to so consistently prevail in the numerous judicial proceedings was likely because of the discipline shown by his legal team in terms of characterizing their case solely as an issue of carrying out Terri's own desire to be removed from artificial life-support.

The arguments presented by the Schindler family's legal team, and those presented in the media by the Schindler's and their various supporters, were much less disciplined. At times the argument was made that Terri would not have wanted her feeding tube removed. This was asserted variously on the basis of either statements she supposedly had made as a adolescent watching television reports about the Karen Ann Quinlan case, or on her Catholic faith which, according to the position of Pope John Paul II, excludes the provision of food and water from the types of "artificial" life-prolonging treatments (such as mechanical respiration) that individuals have an ethical right to refuse.

At other times, however, the argument for maintaining Terri's nutrition and hydration revealed an ethical stance directly opposed to arguments based on her right to self-determination.

For example, in a detailed report on the case written for Florida Governor Jeb Bush, the court appointed Guardian Ad Litem noted that the Schindler family members explicitly stated during court testimony that “even if Theresa had told them of her intention to have artificial nutrition withdrawn, they would not do it” (Wolfson, 2003, p. 14). The report gives this additional description of the Schindler family’s stance toward Terri’s medical treatment:

Throughout the course of the litigation, deposition and trial testimony by members of the Schindler family voiced the disturbing belief that they would keep Theresa alive at any and all costs. Nearly gruesome examples were given, eliciting agreement by the family members that in the event Theresa should contract diabetes and subsequent gangrene in each of her limbs, they would agree to amputate each limb, and would then, were she to be diagnosed with heart disease, perform open heart surgery. (p. 14)

The sentiments of the Schindler family are of course understandable, and may best be attributed to a purely emotional desire to keep their loved one alive rather than any explicit consideration of abstract ethical principles. Other participants in the legal and media debates, however, made statements quite explicitly based on a “right to life” suggesting that Terri should continue to receive nutrition and hydration, not because she would have wanted to, but because of an ethical obligation to maintain life if the means to do so are within reach. A softer version of this argument was revealed in repeated assertions by President George W. Bush and others that end-of-life medical decisions should “err on the side of life.”

At least three other distinct ethical arguments can be identified that were made in support of maintaining Terri’s treatment. Closely related to the right to life argument, disability rights advocates argued that Terri’s nutrition and hydration should be maintained because its discontinuation would reflect a devaluation of the lives of the cognitively disabled. Another



argument heard frequently in the media coverage was one based on parental rights. According to this argument, Terri's mother and father had a fundamental right to maintain her life if they so desired (e.g., "If her parents are willing to take care of her, why not let them?"). Finally, a number of statements made about the case revealed an implicit reliance on the "best interest standard" that is generally considered an important principle in surrogate decision-making, but only if the substituted judgment standard cannot be applied (Buchanan & Brock, 1990). Examples of this range from the oft-cited concern that removal of artificial nutrition and hydration would cause Terri pain and suffering (and thus was not in her best interest), to the assertion made by Schindler attorney David Gibbs in his argument to Federal Judge James Whittemore (and recounted in the motion later submitted to the U.S. Supreme Court) that because of its conflict with Terri's Roman Catholic faith, terminating her nutrition and hydration could "jeopardize her eternal soul."

The sheer volume of commentary on the Schiavo case ensured that a wide range of different perspectives would be applied to understand and argue it. But the more general point should not be missed. In any case where family members must make medical decisions for an incapacitated loved one, there is bound to be emotional anguish and, quite often, interpersonal conflict, regarding the appropriate standard by which decisions should be made. The desire to relieve a loved one's suffering or honor her wishes to terminate treatment invariably conflict with the sadness and potential guilt that are the unavoidable emotional toll of finally deciding that the battle for a loved one's life is lost. It is likely, therefore, that many surrogate decision makers fully understand and acknowledge their obligation to do what their incapacitated loved one would have wanted, but still feel deeply ambivalent about (or even emotionally incapable of) carrying out those wishes.

End-of-life decision-making is also ripe for interpersonal conflict. Although the right to self-determination holds a preeminent place in U.S. case law guiding end-of-life decision-making, this value hierarchy is hardly universal. Individuals differ in their personal desire to control their own end-of-life medical care (Hawkins, Ditto, Danks, & Smucker, 2005), and sharp individual, cultural and religious differences exist in the value ascribed to patient autonomy relative to other decision-making standards such as the right to life or family-based decision-making (e.g., Blackhall, Murphy, Frank, Michel, & Azen, 1995). Family members inevitably bring unique sets of values to the decision-making process and thus clashes between these values seem likely. These value conflicts may often be difficult to resolve because people seldom hold explicit ethical positions that they can readily articulate. Rather, individuals tend to respond to ethical dilemmas based on intuitive, emotion-based moral rules (Haidt, 2001), and thus it may be hard for family members to identify the sources of their disagreement and address them.

The conflict seen in the Schiavo case regarding the appropriate values by which to guide decisions about Terri's care, although unusually intense, was hardly unusual. It would seem the exceptional case when family members experience no emotional ambivalence nor value conflicts when faced with a decision about whether to discontinue life-prolonging medical treatment for an incapacitated loved one.

#### Conflicting Views of Terri's Wishes

A common refrain in the coverage of the Schiavo case was that the entire conflict would have been avoided if only Terri had expressed her wishes in a living will prior to her collapse. More formally known as *instructional advance directives*, living wills are often presented, by the media and the medical establishment alike, as a cure for all that ails end-of-life medical decision-making. If the problem is that people are often too sick to tell others what treatments they want

near the end-of-life, then the solution is to have people write down their wishes when they are still healthy enough to do so. Support for living wills also flows directly from the ethical priority we give to the principle of self-determination. Theoretically, living wills allow people to control their own end-of-life care by communicating their wishes to the surrogate decision makers who can then carry out those wishes on the patient's behalf (Ditto et al., 2001).

This point is crucial because, despite the fact that Terri Schiavo left no written record of her wishes regarding her end-of-life care, it was the court's conclusions about the nature of Terri's wishes that played a central role in the ultimate decision that her nutrition and hydration could be terminated. Testimony by Michael Schiavo and two members of his family indicated that Terri had expressed her wish to be removed from artificial nutrition and hydration based on statements she had made indicating a general desire not to become a "burden" and not to have her life prolonged artificially with "machines" and "tubes." These statements were vague, and their veracity was questioned by the Schindler family, but ultimately the court accepted this testimony as "clear and convincing" evidence of Terri's wishes.<sup>2</sup> It was thus upon the power of these general verbal statements that the courts ultimately decided that it would be honoring Terri's wishes to remove her from the machines and tubes that were maintaining her life.

Among people who approached the Schiavo case without deep valued-based convictions, it was likely the fact that such a momentous decision was based on such less-than-definitive evidence that was the source of their greatest discomfort. For some, concern about the lack of any written record of Terri's wishes was compounded by suspicions about the potential conflict of interest represented by her husband's romantic involvement with another woman. If only there

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<sup>2</sup> Statements offered by the Schindler family suggesting that Terri would not have wanted to be removed from life-support were deemed less credible by the court because they occurred when Terri was a child and referred only to Terri's feelings about Karen Ann Quinlan rather than specifically to Terri's wishes for her own medical treatment.

had been greater certainty about what Terri would have wanted. If only Terri had completed a living will--so goes the lament--all the controversy, bitterness, and heartache that surrounded her final days could have been avoided.

Once again, it is tempting to view the Schiavo case as unique in the extent of uncertainty that surrounded Terri's wishes about the use of life-sustaining medical treatment. In reality, however, uncertainty about the wishes of incapacitated patients is the rule rather than the exception in end-of-life medical care.

First, like Terri, most people die without an advance directive. Despite years of enthusiastic advocacy by major health care organizations and the widespread passage of state and federal law encouraging their use, fewer than 25% of Americans (pre-Schiavo) were estimated to have any kind of advance directive (Eiser & Weiss, 2001). There is some evidence that media attention on the Schiavo case has generated some increased interest in advance directives (Pew Research Center, 2006), but the longevity of this interest and whether it will manifest itself in the actual completion of advance directives is still in question. Rates of advance directive completion are particularly low for some ethnic groups (Caralis, Davis, Wright, & Marcial, 1993; Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998; Murphy et al., 1996) and although high quality data are hard to find regarding the prevalence of advance directive completion among adults in their mid-20's (as Terri was at the time of her collapse), it would seem safe to assume that it too is quite low. Even seriously ill individuals have been found to complete living wills at rates only slightly higher than those found in non-patient populations (Holley, Stackiewicz, Dacko, & Rault, 1997; Kish, Martin, & Price, 2000). Thus, rather than being the atypical case, most families, like Terri Schiavo's, face the task of end-of-life decision-making without written documentation of their loved one's wishes.

Second, even when individuals complete advance directives, these directives seldom provide clear instructions that can be used to guide actual medical decisions. One study, for example, found that only 5% of directives completed by a sample of seriously ill patients contained any specific instructions about the use of life-sustaining treatment (Teno et al., 1997). The majority of the directives were either durable powers of attorney (simply naming the individual they wanted to make decisions for them) or contained only vague instructions with unclear implications for the patient's actual medical condition (e.g., "no heroic measures").

Finally, even when individuals complete directives containing relatively specific treatment instructions, these directives may still do little to improve surrogates' understanding of the patients' treatment wishes. In a study conducted by my research group, we found that allowing a surrogate to review a quite specific advance directive completed by a loved one did not improve the surrogate's ability to predict the treatment preferences that loved one stated in response to a series of hypothetical end-of-life scenarios (Ditto et al., 2001). Moreover, this was true even when surrogates were allowed to discuss the content of the directive with their loved one immediately prior to the prediction task.

There are at least two different reasons why even specific directives may be less helpful than most people might imagine when it comes to clarifying a loved one's end-of-life wishes. First, no directive, no matter how detailed, can possibly anticipate all the medical decisions that might await us (e.g., Brett, 1991). Even specific directives often require that surrogates infer a patient's preference for a particular medical treatment in a particular medical condition, from that patient's statements about similar but not identical treatments or conditions.

Second, when family members act as surrogate decision makers, they have been found to show at least two types of prediction biases that may compound problems caused by the

imperfect mapping of directive statements onto experienced clinical conditions. The first of these is an overtreatment bias such that family members consistently predict that their loved ones will want life-sustaining treatment more often than they really do (Ditto et al., 2001; Fagerlin, Ditto, Danks, Houts, & Smucker, 2001). One way to characterize this bias is that family members tend to “err on the side of life” even when they are trying their best to honor a loved one’s wishes. Another bias that has been documented in both family surrogates and physicians is a projection bias (Fagerlin et al.; Schneiderman, Kaplan, Pearlman, & Teetzel, 1993). That is, when trying to predict another person’s desire for life-sustaining medical treatment, we often err by assuming that that individual will have wishes similar to our own. Although using one’s own wishes to predict another’s is not inherently irrational (many people likely approached the Schiavo case by imagining what *they* would want if *they* were in Terri’s condition), projection has been found to be a common source of misprediction in studies examining the accuracy of surrogate substituted judgment (Fagerlin et al.; Pruchno, Lemay, Field, & Levinsky, 2005). It is not hard to imagine that the beliefs of the various members of Terri Schiavo’s family might have been influenced by this tendency to believe that Terri’s wishes about end-of-life medical treatment were likely to be the same as their own.

#### Conflicting Views of Terri’s Medical Condition

So far, I have argued that family members often bring differing moral standards to bear on difficult decisions about how to treat an incapacitated loved one and there is often uncertainty and disagreement regarding just what that loved one would want if he or she could only say. The Schiavo case, however, was plagued with one additional source of uncertainty that might seem less typical than these others: the uncertainty that surrounded the actual nature of her medical condition.

Space considerations preclude a full description of the intricacy of the two factions' beliefs about Terri's actual medical history, but the opposing positions boiled down to this. According to Michael Schiavo, his wife Terri was in a persistent vegetative state, with no chance of improvement or recovery and was responsive to environmental stimulation only at a rudimentary, reflex level. According to Terri's parents and siblings, Terri was in a condition that is generally referred to as a "minimally conscious state," with the potential for some substantial degree of recovery if aggressive treatment was applied, and was aware of and emotionally responsive to their presence (and perhaps even capable of expressing her wishes and intentions). These dramatically different portrayals of Terri's medical condition added another level of decision-making complexity onto an already challenging situation. If one accepted Michael's assessment of Terri's medical condition, two things reasonably followed: (a) there was little of "Terri" left to save even if saving her was possible, and thus terminating the treatment that prolonged her marginal existence was morally justifiable, and (b) Terri likely would not have wanted to have her life prolonged if she had no significant cognitive function and no chance of ever recovering it. Conversely, if one accepted the Schindler's assessment of Terri's condition, two quite different things could be reasonably concluded: (a) it was morally wrong to deny treatment to a person with some ability to think and reason and a substantial likelihood of recovery, and (b) Terri would likely have wanted her nutrition and hydration continued if she knew that she might be able to recover and regain some reasonable quality of life. Thus, true knowledge of Terri's actual medical condition had dramatic implications for what could be perceived as the "right" decision to make on her behalf, both in terms of the direct moral implications of the act of withdrawing treatment, and in what the nature of her condition would imply about honoring Terri's own treatment wishes.

It is tempting to see the uncertainty and conflict surrounding Terri Schiavo's medical condition as uniquely a function of our limited understanding of vegetative states and the nature of consciousness itself. The issues that seemed so central in the Schiavo case are relatively rare, but the general problem of medical uncertainty is not. In particular, uncertainty about patients' prognoses for recovery often accompanies, and complicates, end-of-life decision-making.

Perhaps the single piece of information that people find most helpful in making end-of-life decisions is a clear sense of whether the patient is likely to regain an acceptable quality of life (Fried & Bradley, 2003; Fried, Bradley, Towle, & Allore, 2002). End-of-life decisions involving older adults with multiple medical problems often generate relatively little conflict because it is clear to all that medical treatment can only prolong an imminent and inevitable dying process. Similarly, hypothetical statements about end-of-life wishes are often stated confidently because they assume an unambiguous prognosis (e.g., "I would *definitely* not want to be kept alive if there was *no* chance that I would recover.>").

In reality, however, prognostic certainty is a rare commodity. Medical prognoses, by their very nature, are statements of probability. Moreover, rather than involving just a single probability of full recovery given one particular treatment approach, the uncertainties involved in real clinical situations are often complex and multiple, involving numerous probabilities representing various degrees of partial recovery and various likelihoods of different types of unfavorable outcomes associated with multiple possible treatment approaches.

As was well illustrated by the Schiavo case, uncertainty about a loved one's prognosis for recovery creates uncertainty and often conflict about the appropriate course of action. No one wants to give up the fight for their loved one's life prematurely, but how can one know for certain that a decision to terminate treatment is premature? If a physician tells a patient's family



that he has only a very slightly chance of recovery, how does the family know for sure that their loved one is not that rare case that will pull through? If family members disagree about their loved one's *future* likelihood of recovery, how can the issue ever be resolved in the *present*? Real end-of-life decision-making taking place in real time almost always occurs in a mist of irreducible uncertainty regarding the patient's likelihood of (full or partial) recovery.

The problems caused by prognostic uncertainty can be compounded by the fact that family members typically have a powerful emotional desire to maintain the belief that their loved one will recover. Psychological research provides clear evidence that motivation can bias assessments of the likelihood of wanted and unwanted outcomes (Ditto, Munro, Apanovitch, Scepansky, & Lockhart, 2003; Weinstein, 1980). Thus, family members who want desperately for their loved ones to recover may often be reluctant to end treatment, maintaining their belief in the possibility of recovery even when the medical probabilities seem clear to more dispassionate observers. Consistent with this speculation, it seems likely that in addition to differences in values and disagreements about Terri's wishes about the use of life-sustaining treatment, another clear source of the intense conflict seen in the Schiavo case was the difficulty Terri's parents and siblings seemed to have had accepting the prevailing medical opinion (confirmed by a subsequent autopsy report) that Terri's brain damage left her with no significant cognitive function and no reasonable chance for recovery.

#### The Legacy of the Schiavo Case

The public attention generated by the final weeks of Terri Schiavo's life will almost certainly spawn well-intentioned efforts to address the difficult issues that surround end-of-life medical decision-making for incapacitated patients. It is crucial, however, that these efforts be more than just well-intentioned.

The Schiavo case was most certainly a compelling family drama, with a storyline that mapped seamlessly onto the broader cultural drama playing out in contemporary red state (Republican Party controlled) vs. blue state (Democratic Party controlled) America. It will be tempting for lawmakers to view the case in this most superficial light, and try to fix it with equally superficial measures. In the sections above, however, my goal was to illustrate that the decision-making challenges that made the Schiavo case so vexing were neither simple nor uncommon. As such, law and policy makers must approach end-of-life decision-making with a full appreciation of both the scope and complexity of the challenges involved. In this final section, I venture a few suggestions about the general form attempts to address these challenges should and should not take.

Clearly the most problematic form legislation could take would be to attempt to require in some way that under conditions of uncertainty, surrogate medical decisions err on the side of life. Such a provision might seem reasonable at first blush, but it is important to recognize that the impetus for the advance directive movement was widespread public concern about the aggressive use of advanced medical technology to prolong the dying process (President's Commission, 1983). Given the ubiquity of uncertainty in end-of-life situations, a requirement to err on the side of life would institutionalize this fear of pointless medical treatment and repudiate several decades worth of state and federal legislation designed to address this very problem.

Moreover, although such a requirement seems to maintain the ethical priority of self-determination (by suggesting treatment only in cases when the individual's wishes are not clear), the end result of the requirement would almost certainly undermine self-determination in many instances. With reference to the Schiavo case, for example, public opinion polls suggest that a clear majority of the American people would have wanted treatment terminated if they were in a

medical situation similar to Terri Schiavo's (Blendon, Benson, & Herrman, 2005; Pew Research Center, 2006). In my own research, we have found that only about 10% of older adults say they would want to receive artificial feeding and fluid if they were in a "coma" with "no chance of recovery" (Coppola et al., 1999; Ditto et al., 2001). The number increases to near 40% if the condition is said to have a "very slight chance of recovery," but this still leaves a substantial majority of individuals in a case similar to Terri Schiavo's for whom a requirement to err on the side of life would result in treatment that opposed their wishes.

Finally, perhaps the clearest result from the public opinion polls conducted in the wake of the Schiavo case is that a substantial majority of the American public, cutting across virtually all religious and political lines, have a distinctly negative reaction to governmental interference in an individual's end-of-life care (Blendon et al., 2005). Although individual Americans clearly differ on the specific values that they believe should guide decisions about the use of life-sustaining medical treatment, most agree that these decisions are a personal matter to be resolved by individuals and their families according to their own moral sensibilities, rather than dictated from outside by judges or, perhaps worst of all, politicians. Based on these data, I suspect that any attempt to use policy or law to impose a value standard on end-of-life decisions (like erring on the side of life) would be responded to poorly by the American public.

This brings us to the opposite approach. One way to address the inherent uncertainty of surrogate decision-making is to impose decision standards on individuals from the outside. A quite different way to address the problem is to maximize individual control over end-of-life decisions by developing policy and law to encourage the completion of more and more specific instructional advance directives.

From a strict self-determination perspective, the push toward greater specificity in living

wills makes perfect sense. Theoretically, the more clearly and precisely an individual can document his or her wishes prior to incapacitation, the more clearly and precisely those wishes can be followed afterward. Specific instructional directives are also appealing from the perspective of both physicians and attorneys. To the extent that advance medical decision-making can mimic the specificity of real time medical decision-making (e.g., “The patient is in medical condition X, and his living will clearly states that if he were to experience condition X he does not want medical treatment Y”), then physicians have not only clear medical instructions by which they can honor patients’ wishes, but also clear legal protection to enact those wishes in the guise of honoring the patient’s right to self-determination.

The problem with this strategy when taken to its logical extreme, however, is that it is unlikely that even a very specific instructional directive will provide the clarity surrogates, physicians, and attorneys seek regarding the wishes of an incapacitated loved one. Suppose Terri Schiavo had documented in her living will: “I do not want life-prolonging medical treatment if I am in a persistent vegetative state with no chance of recovery.” Would this statement, which is more specific than the kind of statements found in most living wills (Teno et al., 1997), have resolved the uncertainty and conflict surrounding this case? By “life-prolonging medical treatment” did Terri mean artificial feeding and fluids? Some people would, others would not. Was Terri in a persistent vegetative state? Her husband says she was, but her parents and siblings disagreed. Did she have a chance of recovery? How big a chance? How big a chance of recovery is big enough that we could all agree that Terri would have wanted to take the risk of spending the remaining years or decades of her life unable to communicate, dependent on others for every need, a shell of the vivacious young woman she once was?

One might argue, of course, that these ambiguities could be addressed with even greater

specification of wishes. But there are two other important problems with a push toward hyper-specificity in advance directives.

First, there is considerable evidence to suggest that people are not capable of making detailed predictions about the specific medical treatments they would want to have used on them in specific medical conditions. A quite extensive body of research from both the medical and psychological literatures reveals that people's predictions about their behavioral and emotional reactions to future situations are often inaccurate (see Ditto, Hawkins, & Pizarro, 2005 or Wilson & Gilbert, 2003 for reviews). In particular, healthy people are poor predictors of how sick people view their condition (e.g., Sackett & Torrance, 1978; Ubel, Loewenstein, & Jepson, 2003), even when individuals are asked to predict their own reactions to future illness (Jansen et al., 2000). This research is consistent with numerous studies showing that preferences for life-sustaining medical treatments exhibit substantial instability over time (Danis, Garrett, Harris, & Patrick, 1994; Ditto et al., 2003; Fried et al., 2006) and can be affected by changes in the respondent's physical and emotional condition (Ditto, Jacobson, Danks, Smucker, & Fagerlin, 2006; Fried et al., 2006; see Spannhake, this volume) or even the way the questions are asked (Forrow, Taylor, & Arnold, 1992). Thus, even if healthy people could be encouraged to document highly detailed treatment preferences in advance of incapacitating illness, it is not at all clear that these preferences should then be taken as a meaningful representation of the preferences these same individuals would have after they became sick.

Second, even if people were capable of generating highly specific preferences about their hopes for end-of-life medical treatment, research suggests that the majority of people have little desire to exert the kind of tight control over end-of-life decisions that is implied by highly specific advance directives. There is little doubt that most people express positive sentiments

toward advance directives in general and laws supporting the general right of individuals to refuse life-prolonging medical treatment if they so desire (Blendon et al, 2005; Pew Research Center, 2006). When asked about their personal wishes, however, many individuals express ambivalence about the need to complete specific instructional directives, and instead seem more positively inclined toward informal discussion of wishes and directives that focus on general values and goals rather than specific treatment preferences (Hawkins et al., 2005). Patients often state that they are quite satisfied leaving end-of-life medical decisions to their families (Holley et al., 1997) and this preference for family-centered over individual-centered decision-making is particularly true of certain culture groups such as Asians and Hispanics (Kwak & Haley, 2005). Because individuals are aware that they cannot have all the facts about their future illness when they are completing their living will, many actually state that in the event of a disagreement between their own documented preferences and the opinions of their surrogate, the surrogate's rather than their own directions should be followed (Terry et al., 1999). Similarly, Hawkins et al. (2005) found that over half of the older adults they interviewed wanted their surrogates to have either "compete" or "a lot" of leeway to override their treatment preferences based on their surrogate's assessment of what was in their (the patient's) best interest (see also Sehgal et al., 1992). Only 9% of participants in the Hawkins et al. study believed that surrogates should have no freedom to override the participant's previous stated wishes.

What this suggests is that rather than striving to provide people with tighter and tighter control over their end-of-life care by encouraging the completion of more and more specific living wills, a more psychologically feasible goal, and one more consistent with the degree of control most individuals actually desire over end-of-life medical decisions, would be to encourage general advance directives and thus a more general form of self-determination. A

commitment to self-determination does not require that people be forced to make decisions they feel ill-equipped to make, but only that people be provided the level of control they desire. The majority of people seem to have little interest in “micromanaging” their end-of-life treatment (Hawkins et al., 2005), and instead want only to gain some general sense of control over the dying process and to reduce the level of burden on their loved ones.

Toward this end, a number of advance directive forms have been developed which focus on general values and goals underlying end-of-life medical wishes rather than on the documentation of specific treatment preferences (e.g., Doukas & McCollough, 1991), and several others combine an emphasis on specific preferences and general goals (Emanuel, 1991). These general directives can be important because surrogates often have inaccurate beliefs about the values and goals their loved one’s wish to guide their end-of-life care. Hawkins et al. (2005), for example, found that in less than one-fourth of the patient-surrogate pairs they interviewed, could the surrogate correctly guess the one value their patient (typically a spouse or parent who they had known for over 45 years on average) had selected as the most important value guiding their end-of-life medical care. Similarly, less than half of surrogates knew the extent of leeway their loved one wanted them to have in end-of-life decision-making, with the majority of surrogates believing that patients wanted to maintain tighter control than they actually did.

In addition to refocusing attention on general goals rather than specific treatment preferences, another important step in this regard would be to encourage the completion of proxy advance directives (e.g., durable powers of attorney for health care), or better yet, directives that combine instructions with the naming of a proxy. What people seem to want most is to have someone they trust make medical decisions for them, in most cases with some general guidance about the values and goals that they want to steer these decisions. Emphasizing the importance of

proxy directives thus helps to reconceptualize instructional directives in a more useful way. That is, rather than the traditional (and problematic) way of framing instructional directives as a direct expression of the patient's wishes that can be followed without interpretation, it is more helpful to conceive of them as input into an informed surrogate decision-making process. Viewing living wills as a way to communicate general wishes rather than as an end in themselves captures the way most individuals want their living wills to be used (Hawkins et al., 2005). Moreover, it suggests the importance of embedding the completion of advance directives in a more extensive process of advance care planning. Clearly the most useful role for instructional advance directives, including specific ones, is as a stimulus for ongoing discussion among one's family members and health care providers. Viewing living wills as the beginning of a communication process rather than its end product, and surrogate decision-making as guided by patients' desire to *inform* rather than *dictate* medical decisions, will lead to an end-of-life decision-making process that is most likely to satisfy the needs and goals of both patients and the loved ones struggling to make decisions on their behalf.

Imagine what might have happened if, prior to her collapse, Terri Schiavo had discussed her wishes about end-of-life care with her husband, parents, and siblings, and informed everyone of the person she wished to entrust with the authority to make medical decisions on her behalf. Would this have made the decisions her family faced easy, or resolved all of the deeply-felt disagreements her family had about her medical care? Almost certainly not. It is not hard to imagine, however, that if everyone in her family knew whose judgment Terri ultimately trusted, and that this individual's decisions were generally consistent with her vision about how she wanted her life to end, her final days would have been much more peaceful, and her story, although still tragic, would no longer be a parable about one way that none of us wants to die.



## Conclusion

Terri Schiavo became a household name in the Spring of 2005, 15 years after she last took a step, spoke a word, or interacted in any meaningful way with the world around her. Indeed, unlike the brand of celebrity we so often see in today's culture--one based almost solely on self-promotion--it was precisely the fact that Terri Schiavo could tell us nothing about herself that led her to become so famous.

In this chapter, my goal was to use the case of Terri Schiavo to illustrate general problems of surrogate decision-making that are most often faced by the loved ones of individuals with chronic and unglamorous diseases like cancer and Alzheimer's disease. It is not surprising that the cases of end-of-life decision-making that have generated the most media and legal attention have involved young adults struck down suddenly in the primes of their lives, and left to languish in persistent vegetative states. Cases like those of Terri Schiavo, Nancy Cruzan, and Karen Ann Quinlan make up only a tiny percentage of all instances where decisions about the use of life-sustaining medical treatment must be made, but attract disproportionate attention precisely because they bring into sharp relief the profound and difficult moral and practical questions that often accompany decisions made near the end of life. Such difficult cases will always exist. No approach to improving end-of-life decisions will ever make it easy, will ever make all families see eye-to-eye, or will ever allow us to know with certainty the true wishes of individuals too sick to speak for themselves. We can, however, with a concerted and collaborative effort on the part of politicians, health professionals, and researchers, work to develop policy and law that can help many families more effectively negotiate the difficult and inevitable challenges of making decisions for loved ones. We can never know for sure, but I suspect that this would be an outcome that Terri Schiavo would have wanted.

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